Persons with
Developmental
Disabilities
Alberta Provincial Board

Charting the Future Direction

1999 – 2009

A paper outlining the history of services for persons with developmental disabilities, the current situation and proposed directions and strategies for the future.

Our Vision: An Alberta that honors and respects the dignity and equal worth of citizens with developmental disabilities.

Executive Summary

The Persons with Developmental Disabilities (PDD) Board Governance Structure was put in place to improve services to persons with developmental disabilities and to give communities opportunities to become involved in the planning and delivery of services. In this first year of governance, we have had many opportunities to receive input at the various community forums and deliberations of the boards. The "Charting the Future Direction Paper" presents three directions to guide the creation of the Alberta that was envisioned in the preamble of the *Persons with Developmental Disabilities Community Governance Act (1997).*

Direction One:	***Persons with Developmental Disabilities will have Opportunities to be Fully Included in Community Life***
Direction Two:	***Services Provided under the PDD Board Structure will be based on Equitable Funding and Access to Resources***
Direction Three:	***The Ability of Communities to Include People with Developmental Disabilities will be Supported***

This paper discusses these directions within the context of relevant literature and policy development for the field of supports to persons with developmental disabilities. A summary of the current situation in Alberta in relation to these directions is provided. Then the paper articulates a vision of the future that could be created using these directions and potential strategies to create this future.

The directions, visions and strategies are presented to assist in creating a climate that will allow options to emerge which will best support individuals design their own futures in their own time schedules. The PDD Provincial Board believes that people with developmental disabilities and their families/guardians must be the primary designers of the future service system. The future is not about specific service models or approaches. It is about respecting personal choice and reinforcing personal control over supports required by people in their life journeys.

The proposed future and strategies presented here will be reviewed multiple times in the months and years ahead, to ensure the PDD Community Governance direction stays aligned with the desires and wishes of all people with developmental disabilities. It will be from this vision of the future and these strategies that approaches to improve services throughout the province will be pursued. Details on specific implementation plans and their timing will be presented in future papers as the Provincial Board, Community Boards, Facility Board and Foundation receive feedback from their stakeholders on the specific changes which should occur to improve services to Albertans with developmental disabilities.

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Introduction

The Persons with Developmental Disabilities (PDD) Community Governance Act (June, 1997, "The Act") in its preamble notes:
...the people of Alberta honour and respect the dignity and equal worth of adults with developmental disabilities;
...it is important that adults with developmental disabilities have opportunities to exercise self-determination and to be fully included in community life;
...the individual needs of adults with developmental disabilities are most effectively met through the provision of services that are based on equitable opportunity, funding and access to resources; and
...the Government of Alberta recognizes, values and supports the ability of communities to respond to the needs of adults with developmental disabilities.

Persons with developmental disabilities and their families in province wide focus groups in 1996/97 defined the following as important in their lives:

- Having strong, positive relationships with my family and significant others
- Enjoying my leisure time
- Being independent
- Having a job
- Being included and participating in the community
- Having choices and being able to make decisions
- Being treated with respect
- Being safe
- Taking care of my health

This paper provides background on the development of services for persons with disabilities, the situation in Alberta today, and then outlines the vision for tomorrow with a list of proposed strategies. These directions and strategies have been built from information which led to "The Act" being established and the community consultations which have been occurring in each region since April 1,1998.

The PDD Provincial Board views the directions in this paper as a guide that will serve to:

- Reach the future envisioned in the preamble of the legislation that set up the community governance structure; and
- Support the many attributes of life that are important to people with disabilities and their families.

Charting the Future Direction is a "living document" that will continue to be changed as the Provincial Board receives feedback and direction from the citizens in Alberta with developmental disabilities and their families and guardians, service providers, local and provincial associations, staff of the PDD Boards and the Ministry.

This feedback will be received in many ways including:

- information provided to the Community and Facility Boards through their on-going consultation, visioning and information sessions in local areas;
- issue identification and resolution in local communities through on-going operations and as part of the business planning cycle for each Board; and
- information acquired from the province-wide satisfaction survey .

The directions in this paper will be reviewed using the information gathered over the year to ensure the Provincial Board stays aligned with the desires and wishes of persons with developmental disabilities. If you have not had an opportunity to provide your opinion to the PDD Boards through the above noted channels or you wish to provide feedback specific to this paper, your comments would be most welcome. A list of the Provincial Board Members and the Chief Executive Officers has been attached to this paper for your convenience.

DIRECTION ONE: *Persons with Developmental Disabilities will have Opportunities to be Fully Included in Community Life*

Changing Philosophies in the Provision of Services

Services to people with developmental disabilities have experienced three distinct eras based on different social and philosophical contexts. Bradley and Knoll (1995) describe three models which have shifted in their dominance during the last three decades:

- medical or custodial model
- developmental or program model
- citizenship or community membership model

Medical or Custodial Model. The first part of this century was characterized by the philosophy of *segregation* which resulted in large numbers of individuals being removed from their families and communities to live in institutional environments.[1] The *medical* or *custodial* model influenced the manner in which services were provided. During the 1960s and '70s, increasing knowledge of the conditions of life in institutions resulted in demands for reform. This inevitably led to a re-evaluation of the prevailing approach to service delivery and the introduction of new philosophies.

Developmental or Program Model. As the pressure increased to get people out of institutions and into communities, the *developmental* model of service delivery emerged during the 1970s and '80s. It was believed that all people, regardless of their disability, could learn and develop skills and should be encouraged to do so. Services became focused on individual "programs" and plans, typically directed by a team of professionals

[1] References to "institutions" made later in the document include the characteristics of segregation based on disability consistent with this description of the medical or custodial model.

whose goal was to teach the skills necessary for the individual to live in the community. Although this approach benefited many individuals, the developmental model also received some criticism. Often skills were taught through elaborate procedures that were removed from the context within which they should be applied (e.g., teaching cooking skills in a day program rather than at home). Even more troubling was the underlying assumption that, for individuals with disabilities, living in the community was a privilege to be earned – not a right of citizenship.

Citizenship or Community Membership Model. In the 1990s, the pendulum has swung almost full circle so that by far the majority of individuals with developmental disabilities now live in communities. The prevailing philosophy of *citizenship* or *community membership* recognizes the right of every individual to live in his or her own community and enjoy the same benefits as do other people. The term "community alternatives" becomes irrelevant, as there is no alternative to the community – it is a universal right of citizenship. Current challenges focus on full community *inclusion* – so that individuals do not live in isolation within their communities, surrounded only by professionals and paid support staff.

Alberta Today

All three approaches can be seen in the current delivery of services throughout Alberta and each approach from an earlier era has tried to incorporate new philosophies within the older model of service.

Institutions or facilities[2] in Edmonton, Red Deer, Calgary and the South Region provide supports to some 800 people. In the 1970s almost 2500 individuals resided in institutions.

Community services are well established throughout Alberta and provide supports to over 8000 individuals with developmental disabilities. The types of services and supports range in approach from the developmental to the citizenship model. Experience has shown that living in group homes or attending segregated day activities can be an isolating experience for individuals, and service providers are continously challenged to promote full inclusion. Increasingly people are understanding that community living is not so much a type of service or a building, but *relationships and activities*. This is resulting in the emergence of shared-living models rather than group homes, the provision of supports that are tailored to the individual, and portability of funds. More and more individuals with developmental disabilities are experiencing relationships with community members.

Alberta in the Future: Inclusion in Community Life

This 10-year plan of the PDD Provincial Board proposes a future where persons with developmental disabilities will have freedom of choice as to where, and with whom, they

[2] Alberta refers to services that have similar characteristics to the description of institutions in the literature as directly operated facilities. For ease of reading the term facilities has been used to describe these services.

live. The Provincial Board believes that achieving inclusion in the future speaks to more than just where a person resides. It also means individuals with developmental disabilities will live as full citizens in interdependent communities and that they:

- Are respected, valued and welcomed by others in their communities
- Are supported to live where they choose to live
- Have opportunities to live on their own or share a home with a small number of other people
- Receive supports based on individual needs and preferences
- Participate in the same relationships and activities that most people choose and enjoy, such as:
  - Strong relationships with friends and families
  - Participation in their communities
  - Meaningful employment opportunities
  - Making decisions about events in their lives
  - Enjoying leisure activities

Strategies for Inclusion in Community Life

...because experience demonstrates that people are more fully included as citizens when they are part of daily community life; and
...because individuals with developmental disabilities and families want to have lives that include the same relationships and activities that most people choose to enjoy; and
...because every individual has unique skills, gifts and aspirations;

the following strategies are proposed:

- Individualized planning will occur which includes identification of the unique skills, gifts and aspirations of individuals and their support requirements

- Individuals receiving supports funded through PDD will be given every opportunity to participate in the same relationships and activities that most people choose to enjoy

- Opportunities to experience new types of supports and services will be supported through education, trial placements and visits to assist people in making the choices they want for the future

- Innovative service models to support persons with complex needs that allow for community inclusion in regular communities will be explored

- The community and facility boards will work co-operatively to develop individual program and funding plans that support the choices of dependent adults who want to move out of institutional services.

* Community Boards will be responsible to fund services for individuals who have to move out of their community because the services are not available within their community

DIRECTION TWO: *Services Provided under the PDD Board Structure will be based on Equitable Funding and Access to Resources*

Cost of Providing Supports

Little literature exists on overall equity in service supports for persons with developmental disabilities. Most of the discussion in the literature in relation to equity focuses on the relative cost of providing services in the community as opposed to in institutions.

This literature does indicate that the overall average cost of community living is less than the average institutional costs (e.g., Ontario Ministry of Community and Social Services, 1997). It should be noted, however, that despite the economic platform, in all situations the underlying rationale for closing institutions was to provide better services rather than to reduce service costs.

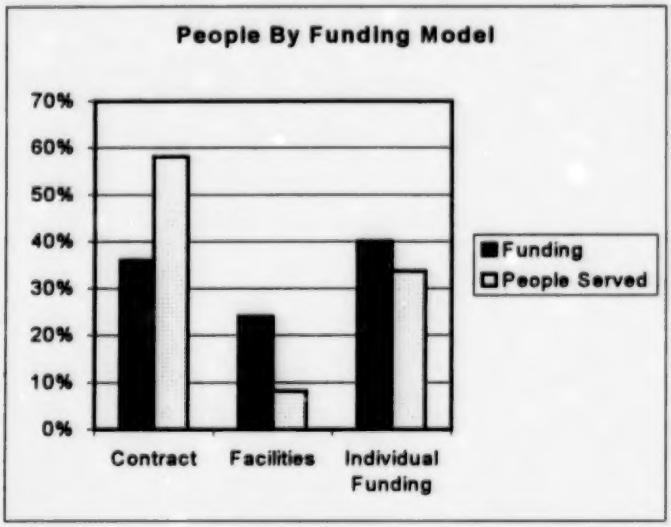
Alberta Today

The manner in which services have been and are currently funded in Alberta reflects the three philosophical models discussed under Direction One above. In the institutional era, government directly operated and funded facilities to provide services to persons with developmental disabilities. As community services developed in response to families who wanted their children supported locally, funding was typically directed (through contract) to the service provider to deliver agreed upon programs. During the 1990s, families requested a stronger voice about what and how services were provided. To facilitate their involvement, funds have been given directly to many individuals to purchase the services that they need, where they choose. It is believed that putting the money in the control of the consumer allows supports to develop in a way that is responsive to the unique needs of that person. Variations of these funding models continue to evolve as efforts are made to promote the autonomy and authority of the consumer, while reducing administrative complexities.

The evolution of funding methods, though supportive of the changing philosophical approaches in the delivery of service, has lead to inequities in ease of administration and questions on equitable distribution of funds. Funding models need to be reviewed to

address: issues of equity, outcomes of service for the individual, and effectiveness of resource utilization.

During 1998/1999 in Alberta, $269 million was budgeted to provide services to adults with developmental disabilities. Facilities were allocated $64.7 million, contracted services $96.6 million and individual funding $107.6 million. The graph below illustrates the amount of funding under each funding model related to the percentage of people served through facilities, community agency contracts and individual funding.



Alberta in the Future: Equitable Funding and Access to Resources

The PDD Board recognizes that in order to fully include persons with developmental disabilities in community life, the current resource distribution among service models must be addressed. The future distribution of funds must have the following characteristics:

- Funding is directed to services which are meeting the expectations of people with developmental disabilities and families
- Variance in funding is due to the support need requirements of the individuals receiving services
- Funding allows for fair pay to the workers supporting persons with disabilities
- Services offering similar supports and producing effective outcomes for people are treated equitably
- Individuals and their families are able to control the funds provided to purchase supports and services
- Funds for service supports are expended on direct support services

Strategies to support Equitable Funding and Access to Resources

...because we need to ensure that the current resource base is equitably distributed; and
...because the current funding model is historical in nature and needs to be made congruent with the direction of full inclusion; and
...because control of the funds needs to be placed with individuals with disabilities and their families to ensure they have choice and a strong voice in directing service;

the following strategies are proposed:

- Design and implement a province-wide method of determining needs and the supports costs for individuals
- Compare costs for similar services, including the level of support and achievement of outcomes, on a province-wide basis
- Promote strategies which actively address fair wages and skill development for staff who provide supports to individuals
- Implement strategies to ensure the funding of services is equitable across the province
- Design and implement methods of individualizing group costs so that individuals and families can make informed decisions about expenditures
- Require that portability of funds be a standard across the province
- Examine the current funding methods in order to simplify administration and address existing inequities

DIRECTION THREE: *The Ability of Communities to Include People with Developmental Disabilities will be Supported*

What is Community?

Central to the understanding of community, as it relates to the inclusion of persons with disabilities, is the concept of common "ties and interests". According to Neufeldt (1988), community develops around commonality. Within neighbourhoods people may unite around common concerns such as neighbourhood safety or barking dogs. Community allows for the development of common experiences and shared beliefs. Voluntary associations and organizations such as self-help groups, religious fellowships, the Kinsmen Club or the local bowling league are examples of communities.

Regardless of the level of disability, there is evidence that commonality is recognized between people with developmental disabilities and non-disabled persons when time and opportunity allow for the relationship to develop (Bogdan & Taylor, 1987). Some people with developmental disabilities find it difficult to develop relationships with people in their communities when they are dependent on professional caregivers. Community members who are provided with the opportunity to develop relationships with people with developmental disabilities demonstrate a capacity for caring and compassion.

Alberta Today

The majority of services offered in Alberta are provided through non-profit associations. The volunteer boards of these associations are made up of hundreds of citizens who want to contribute to their communities. In the province, examples are emerging of persons with developmental disabilities becoming active members of community churches, associations such as Scouts Canada, Elks, and Kiwanis, as well as assisting community leagues and other associations that are open to all community members.

Alberta in the Future: Communities and Persons with Developmental Disabilities

The PDD Board believes that Alberta communities are caring and responsive. Opportunities must be provided to open doors to citizens to allow relationships to develop. It is by seeing each other as community members with common experiences and shared beliefs that people with developmental disabilities will be viewed as full citizens. This future envisions persons with developmental disabilities having the opportunity:

- To serve in leadership roles in the local communities
- To participate in and contribute to the events and associations which make up their local communities
- To have an active voice, not only in decisions that impact their lives, but also in decisions that affect the lives of others in their communities

Strategies to Support Communities and Persons with Developmental Disabilities

...because communities have the capability of welcoming the diversity and unique contributions of all their members; and
...because relationships in communities have the potential of providing creative, personal networks for inclusion;

the following strategies are proposed :

- Provide active education and public communication to highlight the contributions that persons with disabilities and their families make to our communities

- Provide skill development to persons with disabilities and their families to enhance their capacity to participate effectively in groups, committees and public forums

- Support activities (e.g., training, education and self-help groups) that assist persons with developmental disabilities and their families to undertake leadership roles within their communities

- Ensure that the PDD community governance structure supports and encourages decision making at the community level based on input from persons with developmental disabilities, their families/guardians and the local communities

- Align with community groups, organizations and associations who want to have persons with disabilities involved in their organisation and activities

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